

## HIV: Making Medicines Easy

### *Tips for taking them and sticking with your plan*

This handout talks about the importance of giving medicines as your doctor tells you. Younger children must rely on you, the caregiver, to help them remember to take medicines and to take them in the right amounts, at the right time and in the right way each day.

As your child gets older, you can help him learn how to take medicines on his own. This handout provides plenty of tips on how to make taking medicines easier.

#### What are the basics?

When your child has HIV, it's helpful to know about:

1. **Adherence** — Taking the medicines just as the doctor tells you to take them is called “adherence.” For the medicines to work for your child, it is important that they be taken the way your doctor prescribes them. When not taken correctly, medicines may not work, or they may possibly cause harm to your child.

When your child swallows medicines, they pass into the bloodstream from the stomach. As blood is pumped through the kidneys and liver, the medicine is “cleaned” from the blood. Some medicines are cleaned from the blood quickly, while others take longer. How often a medicine is taken depends on how fast it is cleaned from the blood. To keep the right amount of medicine in the blood to fight HIV, it is important to take it on the schedule provided by your doctor.

Taking medicines on the correct schedule keeps the right amount of medicine in the blood at all times and helps the body fight the infection without stopping.

Some medicines get into the blood better if there is no food in the stomach. Other medicines get in better on a full stomach. Taking medicines with or without food, as directed, makes sure that the medicine is absorbed in the best way for that medicine.



2. **Resistance** — Missing doses of medicine or taking less than the prescribed amount of medicine allows HIV to rearrange itself in a way that makes the medicines no longer work. When this happens, we say the virus has become “resistant.” When you hear that HIV is “resistant” to a medicine, it means that the medicine will not work to stop the virus. Resistance develops when the amount of HIV medicine in the blood is not high enough to stop the virus from multiplying. Once HIV becomes resistant to one of the HIV medicines, it stays resistant.
3. **Side Effects** — Talk with your child's doctor, pharmacist or nurse to learn about all of the main side effects of the medicines she is taking. Remember, it helps to know what to expect, but not everyone gets the same side effects from a medicine. Some people never get side effects, while others do. Some side effects may be temporary, lasting only a short time, and some may be easy to deal with. Call your child's doctor, pharmacist or nurse as soon as you think your child may be having a

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side effect from a medicine. It is important not to wait. The sooner a side effect is dealt with, the better it may be for your child.

4. **Support** — Make the effort to work with your child at every age and know that there is support if you need it. The clinic staff will help you in any possible way to help your child take her medicines.

### How do I stay on a schedule?

Each family is unique. Pick a system and schedule for taking medicines that works for your family. As your family changes and your child gets older, be open to trying new systems and making adjustments in the schedule, if needed.

Use the tips offered here that work best for you and your family. They are not meant to be followed all at once:

- Talk to your child’s doctor or nurse about finding a schedule that works for you. They will do all they can to help you.
  - If you have problems or concerns, talk to the clinic staff. They may be able to help you find a better schedule or change the form of the medicine to help make it easier for you and your child. *Never* change the dosing or schedule on your own. Always check with the clinic first.
  - Think ahead about possible changes in your routine. Some families find that it is harder to stay on track on the weekends, while on vacation and during the summer.
  - Work with a trusted day care or school staff member to arrange for medicines to be given as needed.
  - When your child is switched from liquid medicine to pills, ask the clinic staff to help teach your child how to swallow pills.
  - Plan ahead for medicine refills. Mark your calendar or date book with a reminder to yourself several days before the prescriptions need to be refilled.
- Find out all that you need to know about each medicine your child takes:
    - What is the name of the medicine?
    - What is the correct dose?
    - What form is the medicine in (liquid, pill)?
    - How is the medicine taken (with food, without food, with water)?
    - What are the side effects?
    - When should I call my child’s health care provider if my child has a side effect?
    - What should I do if a dose is missed?
    - How is the medicine stored (at room temperature, in the refrigerator, etc.)?
  - Make a chart with the name of each medicine. Have columns for the dose, what the medicine looks like, when it is taken and any other key information. It may help to put a picture of the pill on the chart or tape an actual pill on the chart. Place the chart in a place where you can refer to it as needed. Some parents find that the inside of a kitchen cupboard works well. This is also a good place to list important phone numbers, such as the pharmacy’s refill line.
  - Use a pill box (also called a mediset) and place it out of the reach of young children but in a place where it will remind you every day to give your child his medicines. Most children with HIV take drugs twice a day. Some pill boxes are designed to hold two doses for each day. Most are filled once a week. Allow your child to help, if appropriate.
  - Some parents use a calendar posted in a “can’t-miss-it” place, such as the refrigerator door, and some use alarms or timers.
  - Try using a medicine chart and mark off each dose that is given to your child. A sample chart that you may copy is at the end of this handout.

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- Some parents put a large picture of their child or one of their child's drawings with a big sign that says, "Please give me my medicine" or simply, "Don't forget!" in a place where they will see it every day.
- Color-code the bottles of liquid medicines to matching oral syringes. This can help make giving the right dose easier. *Never* use an eating spoon to measure liquid medicine. Try a marked dosing cup or dosing spoon. Ask your pharmacist for as many as you need. Most times there is no charge for these items.
- If you also take medicine, it may work to coordinate your schedule with your child's schedule.

### What can I do if medicines taste bad?

- Ask the clinic staff to help you figure out the best way to help your child take medicines that taste bad.
- After your child takes "yucky" medicines, try giving a small piece of candy to help get rid of the taste (such as licorice, a Lifesaver or Starburst).
- Sometimes chilling a medicine can help reduce the bad taste. Be sure to ask if this is OK before trying it. Some medicines should not be chilled.
- Some medicines can be taken after a spoonful of peanut butter, yogurt or maple syrup. These foods can help coat the tongue and mask the bad taste.
- Have your child drink ice water, suck on ice chips or eat a Popsicle before taking medicines. This will "numb" your child's taste buds and deaden the taste of the medicines.
- Be creative.

### How can I support my child?

- Be positive. Be consistent. Expect your child to take medicine just as you expect her to put on a coat if it is raining outside. Being consistent with giving medicines as your child grows will pay off. Taking medicines will simply become accepted as a way of life for your child.
- Medicines should always be given with a parent around. Stay with your child until she has swallowed the medicine. Remind your child that you are on her health care team.
- When your child is old enough, make a plan for her to manage taking her medicines on her own. Try to avoid conflicts and power struggles over medicines. If bad feelings arise, adherence and/or the parent-child relationship will suffer.
- If you struggle with getting your child to take medicines or fight about it with her, you may want to try a "reward" system, such as a sticker chart. At some point, your child is likely to rebel against taking medicines. This is normal. Look out for this, and ask your child's doctor or nurse for help and support if this happens.
- As your child gets older, involve her in taking her medicines. This gives her some control over her illness or infection. For example, help an older child fill the pill box. Then, allow her to take on that responsibility. Once your child is doing it alone, still check the box. And, if possible, watch her take her medicines.
- Remember that taking medicines for HIV is not always easy but it is essential to your child's health. If at any time your child misses doses due to forgetfulness, refusal or any other reason, please contact your nurse or doctor right away for help.

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# Medicine Planner

Name: \_\_\_\_\_ Week: \_\_\_\_\_

Pharmacy: \_\_\_\_\_ Phone: \_\_\_\_\_

Medicine Name and Strength		Sun	Mon	Tue	Wed	Thu	Fri	Sat
	Morning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Noon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Evening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Bedtime	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
# per dose: _____ times per day: _____		<i>Special Instructions:</i>						
Medicine Name and Strength		Sun	Mon	Tue	Wed	Thu	Fri	Sat
	Morning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Noon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Evening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Bedtime	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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	Noon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Evening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Bedtime	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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	Noon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Evening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Bedtime	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
# per dose: _____ times per day: _____		<i>Special Instructions:</i>						

## FOR MORE INFORMATION

- Your child's health care provider
- Visit these Web sites:
  - [www.kidshealth.org](http://www.kidshealth.org)
  - [www.pedaids.org](http://www.pedaids.org)
  - [www.seattlechildrens.org](http://www.seattlechildrens.org)
- Read our handouts on:
  - *HIV: Children 0 to 2 years old*
  - *HIV: Children 3 to 4 years old*
  - *HIV: Children 5 to 7 years old*
  - *HIV: Children 8 to 10 years old*
  - *HIV: Children 11 to 13 years old*
  - *HIV: Teens*
  - *HIV Facts*
  - *HIV: Infection Control*
  - *HIV: Talking to Your Child*
  - *HIV: Helping Children Understand the End of Life*
  - *HIV: Talking to Your Child About Sex*
  - *HIV: Teens and Sex*

Some of the material in this handout was adapted from the following Web sites:

[www.4woman.gov/HIV/children.cfm](http://www.4woman.gov/HIV/children.cfm)

[www.aids.org](http://www.aids.org)

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Disclaimer: The inclusion of any Web site link (or resource accessed through a link) does not imply endorsement by Children's Hospital and Regional Medical Center. Seek the advice of your child's health care provider before you act or rely upon any information from these resources.

*Children's will make this information available in alternate formats upon request. Please call Marketing Communications at (206) 987-5205.*

*This handout has been reviewed by clinical staff at Children's Hospital. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's health care provider.*